



Brain Tumour Support Service

Edition 3, 2016

Paediatrics

Index

- 3** Farewell to Anne Miller
- 3** Merry Christmas from the Brisbane Brain Tumour Support Group
- 4** Childhood brain cancer statistics from the Australian Paediatric Cancer Registry
- 5** Australian Brain Cancer Survivorship Study
- 6** Paediatric brain tumours
- 7** 10 quick facts about childhood brain tumours
- 8** Canines and Childhood Cancer
- 10** Children and brain tumours: common concerns and challenges for parents
- 11** Returning to school after tumour treatment
- 13** Caring for yourself when caring for someone with a brain tumour
- 14** Gamma Knife: Treatment with Leksell Gamma Knife Perfexion

Dear Friends

Welcome to the third edition of the newsletter for 2016.

This issue focuses on paediatrics. Did you know that brain tumours are the most common form of solid tumour amongst children?

In this issue we bid farewell to one very special Cancer Council Queensland volunteer, Anne Miller.

Anne volunteered as the editor of the Brain Tumour Support Service newsletter for over 24 years. Her dedication and support was appreciated and will be missed.

We also have a selection of articles that relate to paediatric brain tumours. Firstly, a very detailed overview of childhood brain cancer statistics by Danny Youlden, Biostatistician at Cancer Council Queensland.

Dr Rob Campbell and Dr Martin Wood from Brisbane Clinical Neuroscience Centre provide their extensive professional insight on paediatric brain tumours as well as the latest on intraoperative MRI and functional MRI.

We have an informative and heart-warming article from our friends in the US, Amy McCullough and colleagues, who provide insight into the benefits of canine therapy for childhood cancer.

Helen Wilson and Nicola Morgan from RedKite have written an insightful article - It's never over, which covers common concerns and challenges for parents of children with brain tumours. Karen Prain from Brainchild Foundation follows on with an article about returning to school after a tumour.

We also spoke with Cancer Council Queensland Cancer Support Specialist, Sylvia Burns on how to care for yourself when caring for someone with a brain tumour.

Keep an eye out for an invitation to participate in Brain Tumour Research entitled Australian Brain Cancer Survivorship Study and Living Now with Low-Grade Glioma, which Dr Danette Langbecker is involved with.

To finish, we have an interesting article about Gamma Knife surgery. Happy reading!

Brain Tumour Support Service Newsletter Editing Team

For more information contact btss@cancerqld.org.au

Donate now

Your donations help fund our research and support services for Queenslanders affected by brain cancer and benign brain tumours, including provision of the Brain Tumour Support Service. Donate online at www.cancerqld.org.au or call our Donor Hotline **1300 66 39 36**

13 11 20

Call 13 11 20 for cancer and brain tumour support information, emotional and practical support. Our Information and Support Coordinators can also refer you to Cancer Council Queensland support programs and other community services.

This free and confidential service is available Monday to Friday 9am–5pm (excluding public holidays) and is provided thanks to the generous donations and support of Queenslanders.

Brain Tumour Information Sessions 2017

Mindfulness

February 2, 2017

Learn skills to assist with coping with a brain tumour through mindfulness meditation practices and guided group discussion.

Finances and brain tumours

August 3, 2017

Information about early access to superannuation and insurance, applying for Centrelink and managing change in financial circumstances due to cancer.

Sessions are held at Cancer Council Queensland, 553 Gregory Terrace, Fortitude Valley QLD 4006.

Stay tuned for details of more information sessions in 2017.



Watch this space!

We will be evaluating the Brain Tumour Support Service shortly, and we want to hear from you. At Cancer Council Queensland our goal is to provide you with a service that is informative and supportive, but to do that, we need your feedback. Stay tuned for information on how you can have your say.

Farewell to Anne Miller

By Rebecca Blower, Community Support Coordinator, Cancer Council Queensland

After 24 years of service we say goodbye to one of Cancer Council Queensland's most dedicated volunteers.

Anne started as a volunteer at Cancer Council Queensland in 1992 following a move to Australia from England. A thyroid tumour prevented her from continuing her work as a high school home economics teacher so she took up volunteering as a way to socialise and keep herself busy. Having been personally affected by cancer, Cancer Council Queensland was a cause close to Anne's heart.

For over 24 years, Anne has worked tirelessly as the passionate volunteer editor of the Brain Tumour Support Service newsletter – I'm sure many of you enjoyed her editorial each edition. When asked if she had undertaken any previous roles her response was, "No, I thought I would start at the top!"

Anne's motivation for volunteering stems from pure enjoyment of her work and the social aspect that came with it, with many fond memories of CCQ social events over the years. For Anne, the highlight of her volunteering was the friendships (and in one instance, romance!) that were fostered on her weekly visits to our Brisbane office.

Her role was not without challenges. Anne recalls the biggest change she witnessed at CCQ – the introduction of computers! Whilst she eventually got the hang of typing, email proved more difficult (I'm sure many of us can relate!).

When asked for her advice to other volunteers or people thinking about volunteering, Anne's message is simple, "Just get stuck in and get onto it".

Cancer Council Queensland would like to sincerely thank Anne for her



Anne Miller receiving a certificate of appreciation at a special afternoon tea last month.

dedication and support to the Brain Tumour Support Service over the past 24 years. Her efforts will be missed.

And as Anne would say, "Until next time, stay happy, keep well and keep smiling".



Merry Christmas from the Brisbane Brain Tumour Support Group

The Brisbane Brain Tumour Support Group marked their final session of the year with a very festive celebration which included Christmas carols, a Secret Santa Steal and food galore!

This vibrant, lively bunch meet on the first Thursday of every month (except January) from 10am – 12pm at Cancer Council Queensland, 553 Gregory Terrace, Fortitude Valley. The group is open to patients, carers, and families (18+) for both malignant and benign brain tumours, no registration necessary.

The next session will be held on Thursday, February 2. For more information about the support group, contact braintsg@gmail.com or call 13 11 20.

Childhood brain cancer statistics from the Australian Paediatric Cancer Registry

By Danny Youlden, Biostatistician, Cancer Council Queensland

Cancer Council Queensland funds and manages the Australian Paediatric Cancer Registry (APCR), a complete national register of all cancer cases for children between the ages of 0-14 years who have been diagnosed with cancer since 1983.

This valuable source of information is the sole Australian population-based registry specifically for childhood cancer and it is one of only a few national childhood cancer registries in the world.

Around 700 children are diagnosed with cancer each year in Australia. Tumours of the central nervous system (CNS), which are mostly brain cancers, are the second most common type of cancer diagnosed among Australian children, with approximately 170 cases per year or 23 per cent of all childhood cancers (Figure 1). The number of children diagnosed with brain cancer has been steadily increasing and is now 45 per cent higher than 30 years ago. The reasons for this increase are unknown. Astrocytomas are the most common subgroup of childhood brain tumour, responsible for 40 per cent of diagnoses, followed by intracranial and intraspinal embryonal tumours (such as medulloblastoma) which account for a further 19 per cent of all CNS tumours.

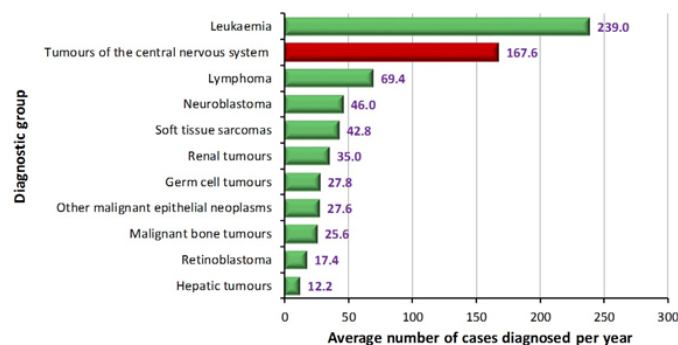


Figure 1: Incidence counts for childhood cancers by diagnostic group, Australia, 2009-2013

In accordance with international standards for childhood cancers, the APCR includes brain tumours of benign or uncertain behaviour, such as pilocytic astrocytoma. The reason for this is because the symptoms, prognosis and late effects are similar for children whether or not the brain tumour is malignant (cancerous) or benign (not cancerous). Just over half (56 per cent) of CNS tumours

are malignant, about a third (37 per cent) are benign, and 6 per cent are classified as uncertain.

Tumours of the CNS are somewhat more common in boys (54 per cent) than girls (46 per cent). CNS tumours are also most common among younger children, with 41 per cent of CNS tumours diagnosed among children under 5 years of age.

Sadly, around 100 children die from cancer each year in Australia, on average. Tumours of the CNS were the leading cause of cancer-related deaths, with 39 deaths per year (or 40 per cent of the total). The subgroup of medulloblastoma accounted for one-third of brain cancer deaths (33 per cent), followed by astrocytoma (26 per cent). In contrast to some other types of childhood cancer, such as leukaemia, the mortality rate due to brain tumours has not changed significantly in Australia since 1983.

The most recent figures available (i.e. for the period 2004-2013) show that five-year relative survival for children with CNS tumours is 74 per cent. This has improved from 66 per cent for the period 1983 – 1993, but is still lower than for most other types of childhood cancer (84 per cent). There are large differences in survival depending on the type of CNS tumour, with five-year relative survival ranging from 50 per cent for children with some forms of glioma up to 84 per cent for those diagnosed with astrocytoma (Figure 2).

The APCR will continue to provide the foundation for epidemiologic research into this rare but significant childhood disease.

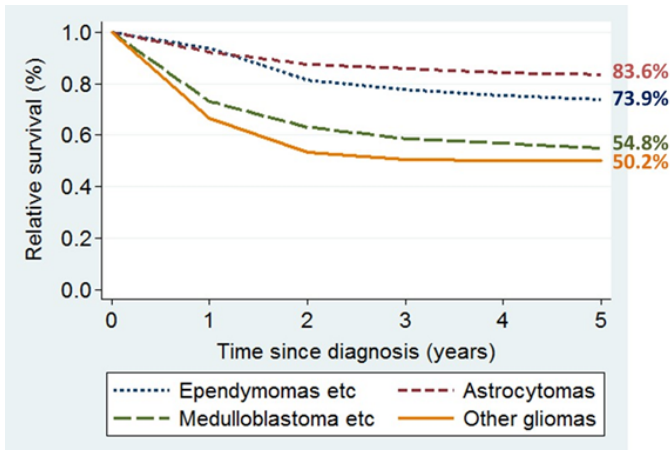


Figure 2: Relative survival for childhood CNS tumours by diagnostic subgroup, Australia, 2004-2013

The Australian Paediatric Cancer Registry will continue to provide the foundation for epidemiologic research into this rare but significant childhood disease. Our aims are two-fold – first, to deliver complete national information about childhood cancer and, second, to facilitate research to improve outcomes for all children who are diagnosed with cancer in Australia.

Australian Brain Cancer Survivorship Study

What is it like to be a long term survivor of brain cancer?
Or to support someone who is?



Who Can Participate?

Adult 18 years & over living in Australia who:

- Has been diagnosed with any type of glioma (e.g. glioblastoma, astrocytoma) at least 2 years ago

OR

- Is a family member or friend and the main provider of physical, practical or emotional support to an adult diagnosed with any type of glioma at least 2 years ago

Participate in our research study to understand the issues affecting people who have or have had brain cancers and their families.

Complete our survey online or by mail.

For more information, go to

survey.qut.edu.au/f/184646/7c13/

or phone Dr Danette Langbecker on (07) 3176 5356.



Paediatric brain tumours

By Dr Rob Campbell and Dr Martin Wood, Brisbane Clinical Neuroscience Centre

Tumours of the brain and spinal cord do not discriminate by age and whilst they occur much less commonly in children than in adults, they cause more deaths than any other cancer under the age of 20.

Since the Lady Cilento Children's Hospital opened in 2014, approximately 80 children have been diagnosed and treated for various tumours of the brain, spinal cord, and nervous system. 40 families each year hear the words that every parent dreads, "your child has a tumour". For that patient and family, their life irreversibly changes in the blink of an eye. Through the network of hospitals managed by Children's Health Queensland, based primarily at the Lady Cilento Children's Hospital at South Brisbane as well as the Townsville Hospital and the Gold Coast University Hospital, children receive state-of-the-art treatment and care.

Brain tumours commonly present with symptoms including headaches, loss of balance, early morning vomiting and other symptoms, depending upon the exact location of the tumour. Symptoms often develop over a six to eight week period. Unfortunately, this serious diagnosis is often not considered at the beginning of each child's illness and children often visit their family doctor and emergency department clinics on more than one occasion before the diagnosis is finally made. With less than 40 diagnoses per year it is most unlikely that the average general practitioner will ever see a child with a tumour in his career.

Tumours may also present with drawn out symptoms of visual failure, growth impairment, or the new onset of a squint as the only symptom of the tumour's presence. Some tumours present with epilepsy and may be difficult to diagnose without high definition magnetic resonance imaging of the brain.

A team of trained children's neurosurgeons and paediatric neuro-oncologists work together in providing care and coordinating the delivery of service for every case in Queensland.

In almost all cases the first treatment is surgical, followed by chemotherapy and, depending upon the child's age and the subtype classification of the tumour, radiation treatment may also be used. Some tumours such as the juvenile pilocytic astrocytoma of the cerebellum have a very good prognosis with survival prediction approaching 95 per cent at 20 years. Unfortunately, other tumours follow a very malignant course and ultimately prove fatal in a much shorter timeframe.

Tumours are classified by their identification of their cell type as seen under the microscope. Typically, tumours

are either astrocytoma, ependymoma, medulloblastoma, or other rarer disease types. Tumours may affect the pituitary gland, the pineal gland, and the optic nerves and are named accordingly based upon their site of origin.

Over the last 10 to 20 years scientific discovery has led to the recent recognition of molecular subtype description of tumours which better predicts both prognosis and responsiveness to various treatment protocols. It is highly likely that in the future the molecular description of the tumour will become much more important in decision management about treatment options than the older microscopic classification system. All such molecular diagnostic services are available through the pathology departments of our treating hospital network.

Tumours of the spinal cord occur much less frequently than brain tumours, although the disease type may be identical to what is seen in the brain itself the anatomy of the spinal cord determines the speed at which symptoms develop predominantly relating to pain and partial or complete paralysis of legs, arms and bladder function. Sometimes emergency surgery is required to relieve the pressure on the tumour and a second operation may then be scheduled to maximise tumour removal prior to chemotherapy treatment.

Tumours of the nervous system, most commonly seen in the setting of neurofibromatosis type I, are almost always benign and rarely require radical surgery other than for relief of functional disability or cosmetic concern.

Occasionally the brain and spinal cord may be directly affected by tumours of the head and neck region or of other abdominal organs spreading to the brain and spinal cord either by metastasis or by direct invasion. Again neurosurgical management may be required to achieve disease control, followed by systemic chemotherapy and or radiotherapy.

The neuro-oncology service at the Lady Cilento Children's Hospital works in partnership with numerous Queensland and international University researchers and have contributed to numerous landmark discoveries and publications around the world within the scientific literature. All children diagnosed with brain or spinal cord disease will be considered for entry into a clinical protocol trial to ensure that their treatment is equal to care delivered in a global network of children's brain

tumour services. The small numbers of cases seen in Queensland (and in Australia) are pooled together to form a much more powerful group of patients around the world to determine the effectiveness of treatment and measure the clinical outcome both in terms of disease control, recurrence rate, and quality of life outcome measures. Queenslanders should be proud of the global contributions of the clinicians caring for children and families affected by brain tumours in the 21st-century.

The diagnosis of a brain tumour in a child 100 years ago was one of, if not the most, formidable diseases diagnosed by children's specialists. Advances in treatment - diagnostic imaging, surgical techniques, chemotherapy and radiation treatment - saves many children and now offers others a much more positive outlook. Whilst the disease remains formidable with challenges that cannot be cured by surgery alone, multidisciplinary team management ensures that every child and their family receive the best scientific-based treatment available.

For more information, please discuss your specific questions with your treating specialist. Your general practitioner will be kept advised and updated throughout your child's treatment and your general practitioner would be welcome to make direct contact with your child's neurosurgeon or paediatric oncologist if any specific questions are raised.



10 quick facts about childhood brain tumours

1. In Queensland there are around 40 cases per year.
2. Half of cases occur in the cerebellum.
3. Hydrocephalus occurs frequently and often requires a shunt.
4. Surgery is often followed by chemotherapy.
5. Tumours of the pineal gland can be diagnosed by blood tests alone.
6. MRI imaging offers the best view of the tumour however CT scanning is still frequently used for rapid management decisions.
7. Tumours affecting the pituitary gland cause hormone deficiency or hormone excess in some cases.
8. Neurofibromatosis patients are assessed each year for the possible development of brain or spinal cord tumours.
9. Ophthalmologists monitor eye function to help measure tumour activity.
10. Epileptic seizures rarely occur when the disease is only in the cerebellum.

Canines and Childhood Cancer

By Amy McCullough, PhD, American Humane Association, Molly Jenkins, MSW, American Humane Association; Ashleigh Ruehrdanz, MPH, American Humane Association

While the incidence of childhood cancer has increased slightly over the past 20 years, mortality rates have drastically decreased, with five-year survivorship currently near 83 per cent.

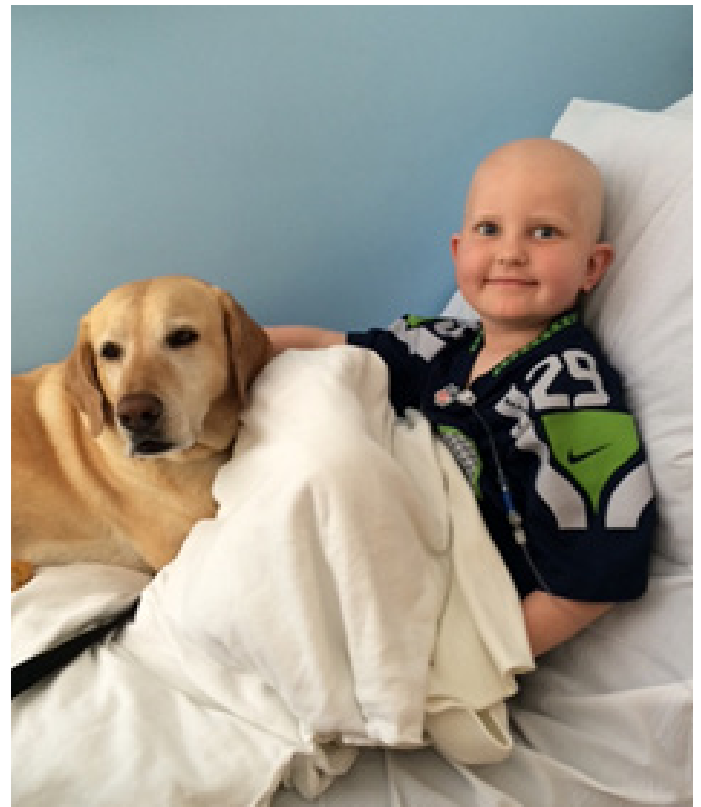
However, the psychological impact the disease and treatment have on childhood cancer patients and their families remains a concern. Childhood cancer diagnoses not only affect patients, but may also have serious implications for their parents/guardians, siblings, and relatives. Children with cancer and their families not only cope with physical challenges, but are also prone to psychosocial and behavioural issues including stress and anxiety, trauma, depression, loneliness, and strain in their significant relationships (Fotiadou, et al. 2008; Norberg & Boman 2008; Jenkins, et al. 2012).

Animal-assisted interventions (AAI) include both animal-assisted therapy (AAT) and animal-assisted activities (AAA), and hold promise for children with cancer and their families. Not only are AAIs accessible and affordable, but research also suggests that animals can provide numerous benefits for people from all ages and walks of life (Nimer & Lundahl 2007; Endenburg & van Lith 2011). Reported benefits of AAIs include reduced stress and anxiety; decreased blood pressure and heart rate; distraction from worry or pain; unconditional support and acceptance; increased opportunities for physical touch; improved social skills that lead to healthy relationships; enhanced self-esteem; and increased motivation to actively participate in treatment (Fine 2010; Friedmann, Son, & Tsai 2010; McCardle, et al. 2011).

From a paediatric standpoint, Vagnoli, et al. (2013) found that children who had a therapy dog present during a venipuncture procedure exhibited less distress, stress and anxiety than those children who did not have a dog present during the same procedure. Urbanski and Lazenby (2012) found that paediatric populations could benefit in myriad ways from the introduction of animal-facilitated therapy in hospital settings, including helping to normalise the hospital environment, improving their mood, increasing their socialisation and decreasing their fears. Multiple studies examining therapy dogs' impacts on hospitalised children have discovered that the dogs help make the hospital feel more 'like home,' in part because dogs are familiar and more similar to children's typical environments (Bardill & Hutchinson 1997, p. 20; Wu, et al. 2002).

Moreover, in a recent study examining the reactions of paediatric patients, their families, and medical staff to the introduction and incorporation of AAAs into a child's hospital in Italy, Caprilli and Messeri (2006) found that children reported their mood to be pleasurable due to the therapy dog's presence. Additionally, Marcus, Blazek-O'Neill and Kopar (2013) found that the introduction of therapy dogs in an adult cancer infusion centre resulted in patients feeling that they were a positive addition to their treatment and determined that therapy dogs may be a valuable tool for addressing a variety of cancer-related symptoms by reducing stress and increasing relaxation.

While many studies have documented the benefits of AAIs, the majority of these findings have largely been anecdotal and the field has consistently struggled with developing and conducting rigorous research (Johnson, Odendaal & Meadows 2002; Kazdin 2010). Many argue that this lack of evidence-based research has hindered the ability of AAIs to be recognised as viable treatment options for people in need, particularly by those in the research, funding, and healthcare fields (Palley, O'Rourke, & Niemi 2010). Although therapy



Therapy dog Bailey



Therapy dog Bear

dog programs are common in children's hospitals throughout the United States, existing evidence concerning the effectiveness of AAls in paediatric oncology settings is very limited. Additionally, there is a general lack of scientific research on how AAls may impact the therapy animals.

Overall, there are crucial gaps that must be filled if AAls are to be considered feasible, effective, safe and ethical modes of adjunctive treatment. American Humane is currently implementing a study called, 'Canines and Childhood Cancer', which has the unique potential of advancing our knowledge in the fields of paediatric oncology and AAI through rigorous and ground breaking research. But, perhaps even more importantly, this study may improve childhood cancer treatment by providing valuable evidence to support an adjunctive treatment modality aimed at providing the comfort of a therapy dog to children and families. Findings are anticipated in mid-2017.

For more information on this study, visit caninesandchildhoodcancer.org



Children and brain tumours: common concerns and challenges for parents

Helen Wilson, Social Worker and Nicola Morgan, Senior Communications Coordinator – Redkite.

Anyone who has experienced the shock of a brain tumour diagnosis will understand the disruptions to day-to-day life and the emotional challenges that follow.



When a child is diagnosed, the issues faced by their family are quite different to those presented by adult brain tumours, and also by other childhood cancers. Parents who have connected with Redkite's support team tell us that help from family, friends and the community, and connection with others who have had similar experiences, are crucial in helping them stay strong and hopeful.

Children with cancer tend to have longer hospital admissions than adults. This is particularly the case if they are having chemotherapy, which is likely to be more intensive than it is for adults. A carer is required to be with the child most of the time during treatment and rehabilitation, which often means at least one parent taking extended time off work.

This reduction in income often comes at a time when costs associated with treatment start to rise (for example travel and accommodation for those not living near a major hospital and medical expenses). If there are other children in the family, often one will stay at home to care for them, while the other stays with the sick child. This can affect family functioning and place pressure on the parents' relationship.

Treatment, hospitalisation and the after-effects of the experience all impact on a child's development. Children

who have finished treatment may have difficulty meeting milestones, and this may continue into adolescence and young adulthood. These 'late effects' tend to become apparent about 12 -24 months after treatment finishes. Often it is not until a normal developmental stage is reached that a delay becomes evident. As such, the child may acquire skills at a slower rate than his or her peers.

The side effects of surgery may also impact on the child's behaviour and temperament. Reconnecting with 'the child within' may take time and patience. Expressive therapies such as art and music, and investment in quiet family time, may help this process. Of course, every situation is unique. Some children will require minimal (or no) treatment and some will have no discernible after-effects.

Parents also talk about the worry of recurrence, the high levels of care required for long periods, and the ways community resources become increasingly limited as time passes. A common theme in many conversations with parents is: 'It's never over.' The fear of recurrence combined with ongoing physical issues and related emotions become a new reality for many families.

A clear message from families is that a strong support system is vital for child and family health. The most effective support networks involve extended family, friends, local community and professional services, all contributing in some way to assist the family. Support from peers is also highly valued. Organisations such as Cancer Council Queensland, Camp Quality, CanTeen, Brainchild and Redkite provide different opportunities for children and young people, as well as their parents and grandparents, to link with others who understand what it's like to live with a childhood brain tumour. Families tell us it helps to know that your feelings are natural and normal – and that you're not alone with these challenges.

Redkite is a national organisation offering support to children and young people (24 and under) with cancer, and those close to them. Our services include financial assistance, education and career support, and information and counselling.

Returning to school after tumour treatment

By Karen Prain, Brainchild Foundation

It is a scenario familiar to many of us – your child has been ill, diagnosed with a brain or spinal cord tumour and is now either in the process of undergoing treatment or has completed treatment.

Their treatment may consist of surgery, radiation therapy, chemotherapy or a combination of the three. The whole experience is a blur of anxiety and uncertainty. Although this time is chaotic, there is a network of health care providers and charitable organisations available to you during hospital visits and stays. They can provide a wealth of information and support. But what happens when your child is able to return home and get back to their normal life? What about going back to school?

Returning to school following treatment is a huge milestone. Some children even return to school during the course of their treatment. Either way, it is important to consider that your child is likely to look and behave differently to the way they did before their diagnosis and treatment. We all know that unfortunately, brain and spinal cord tumour treatments come at a cost. The side effects of treatment can be many and varied, and the severity of those side effects can also range considerably between children. When a child returns to school following diagnosis and treatment, side effects may be evident in the following ways:

- Changes in physical appearance. There can be numerous changes in physical appearance, however the most common are hair loss and weight gain or loss. Other physical changes may include the presence of central lines, dressings, nasogastric tubes, wheelchairs and any other treatment related items. Even subtle changes to a child's skin tone or posture can contribute to the changes in appearance that other children will notice upon a diagnosed child's return to school.
- Physical limitations. Physical limitations following treatment are common, and they can range in nature and severity. Mobility can be affected, and can vary from subtle reductions in co-ordination, to profound loss of mobility requiring a wheelchair. Fatigue is common, regardless of how mobility has been affected. Hearing loss or loss of vision can also be subtle or severe and can have a large impact both socially and academically upon returning to school. Eating habits may also pose a physical limitation for some children, particularly those who still require nasogastric feeds upon their return to school. The

presence of nausea and/or vomiting will also influence a child's eating habits.

- Cognitive changes. It is common for children to experience changes to their cognitive function, particularly if they have been treated with radiation therapy. Again, the degree ranges between children, however, it is common for them to experience a decrease in their attention span, inability to concentrate and poor memory. This will obviously have a great impact on learning, as these issues hinder the ability for children to retain new knowledge. It is also possible they may forget things they learnt prior to diagnosis and treatment.

It is clear that for children diagnosed with brain and spinal cord tumours, returning to school can pose many challenges. All of the issues mentioned (and this is by no means an exhaustive list), have the potential to reduce a child's confidence and self-esteem. This, in turn, can erode their motivation and willingness to 'have a go'. If we want their return to school to be a positive experience, it is vital that parents and caregivers take a little time to plan ahead.

It is important to discuss returning to school with your child. Ask them how they feel about it. What are they looking forward to? What are their concerns? Some children will be eager to get back to school and won't express too much concern over any of the changes that have affected them. If this is the case, share their enthusiasm. For those children who are not so keen, it is important to acknowledge both their positive and negative views. Areas of concern must be discussed rationally, always with a view to resolving the perceived problem or fear. Some children may resist returning to school, therefore it is important to discuss plans with them early, and allow them to be involved with that planning. Liaise with your child's medical team, allied health staff, and school, and involve your child in discussions where appropriate.

It is essential to keep your child's school informed of their progress during treatment, so they are also able to plan for their return. Children will often have different and/or greater needs than before their diagnosis, and schools need time to organise the appropriate supports.

You should also consider requesting peers to be informed of your child's condition. This goes a long way in reducing negative attention upon their return. Other children will be more respectful and considerate if they have some understanding of what your child has been through.

It is important for families to be prepared for these challenges, and to seek support in working through them. Medical and allied health services are vital to supporting a child's positive recovery post treatment. Charitable organisations also play a role in assisting children, and families can connect with them via health care providers. Recovery following treatment takes time, often years, and children may not fully regain the physical or psychological function they had prior. It is important to recognise your child's abilities and

strengths following treatment, and nurture them. This will boost your child's confidence and self-esteem and, in turn increase their motivation. Recovery is about supporting children to be all that they can be, regardless of their limitations.

Brainchild Foundation Educational Scholarships

The Brainchild Foundation supports children diagnosed with brain and spinal cord tumours. One of the ways we support diagnosed children is through our Educational Scholarship Program.

This program provides private tutoring support, and all children with a confirmed brain or spinal cord tumour diagnosis are eligible to apply. Further information is available by emailing: education@brainchild.org.au



Living Now with Low-Grade Glioma

What is it like to be diagnosed with a low-grade glioma?
How do you adapt to this change in your life?
Or how do you make sense of your experience?

Who Can Participate?

Adults 18 years & over who:

- Have been diagnosed with a low-grade glioma 3 months to 10 years ago
- Can communicate in English

This study aims to understand the ways people with a low-grade glioma adapt to their illness, what resources they use and how they cope....

Participants will be asked to take part in a 60-90 minute interview with research interviewer, Dianne Legge at the Olivia Newton-John Cancer & Wellness Centre.

To register your interest or learn more, please contact Dianne Legge on 03 9496 3315 or dianne.legge@hdr.qut.edu.au.

This study is being undertaken by Dianne Legge as part of a Masters of Applied Science (Research) at Queensland University of Technology, and has been approved by Austin Health Human Research Ethics Committee Reference Number HREC/16/Austin/184.

Caring for yourself when caring for someone with a brain tumour

By Sylvia Burns, Cancer Support Specialist, Cancer Council Queensland

As a partner or caregiver, you too experience the impact of brain tumours. When someone close to you is moving through a brain tumour diagnosis, you may find yourself struggling to manage appointments, understanding treatment and effects, as well as confronting fears for you and your loved one's present and future wellbeing.

Many caregivers find themselves closely involved in discussions with treatment teams and shouldering additional responsibilities, particularly when treatment is ongoing and debilitating or the tumour is no longer responding to treatment. Roles and responsibilities often change and you may face relationship pressures and the reactions and concerns of other family members.

Caring for someone you love can be a rich and rewarding experience. It can also be demanding, draining and isolating. With your partner or loved one facing so many challenges, it can be natural to put your own feelings and needs on hold. While this can be okay in the short term, it can lead to exhaustion and health problems over time. Making sure you care for yourself and have the support you need, will ensure that you can be there to care for your loved one throughout the journey, however long it takes.

Tips for caring for yourself

- **Work with difficult feelings** – Feeling stressed, down, fearful, on edge or irritable is normal. Caregivers can experience a rollercoaster of emotions in the face of brain tumours and the extra demands of providing care and support to someone close. Feelings of resentment and anger may arise and lead to shame and guilt. Accepting these feelings as a natural response to the difficulties you are facing can help you let go and move forward.
- **Find someone you can confide in** – Talking problems over with a partner or trusted friend can help lighten the load and make sense of your feelings. A carer support group, professional counsellor or spiritual support are other useful sources of information and support. Reaching out is a survival skill that can help you maintain perspective and balance in difficult times.
- **Stay connected to the outside world** – The demands of caring can mean that other roles and interests slip away. Keeping up some of your usual activities can provide a refreshing break and maintain a sense of yourself in the caring relationship.
- **Invest in your physical health and wellbeing** – Eating well and exercising regularly can help you to cope with stress and maintain your energy and manage fatigue.
- **Make time to lighten up and relax** – This may seem frivolous or a luxury when you are extra busy and pushed

for time. However, taking a mini-break just to step out into the garden and breathe, or 20 minutes to read or listen to uplifting music, are small steps that prevent the build-up of stress and frustration.

- **Be kind and have reasonable expectations of yourself** – It is normal to feel a little frayed around the edges with the extra demands and concerns you are shouldering. Be aware of the tendency to expect too much of yourself and make time to reflect on your achievements. Prioritising what is most important in each day and letting go of previous standards, can help you stay flexible and in touch with what is needed now. Practicing saying no and handing over tasks to someone else are small gifts to both yourself and others.
- **Gather the information you need** – Having information about brain tumours, treatments and what you might expect can help you feel prepared. Take the time to work out what you need to know and discuss this with the treatment team. Ensure that you have contact names and numbers of key health professionals and services and keep these in one place. Knowing where to find information when you need it can help you feel less stressed and more in control.
- **Ask for and accept help and support** – People generally find it hard to accept or ask for help. Some feel it is their role to shoulder all the responsibility, others feel guilty or are concerned about burdening friends and family who already have busy lives. Generally, however, people who care about you feel better if they can be useful in some way. Make a list of all the things that would help you and show it to people when they ask what they can do. It can also help to find out about available health and community services in your area from your GP, or treatment team. Formal respite options can also give both you and your loved one a welcome break from each other.
- **Think of your wellbeing as a bank account** – The demands of caregiving can mean that your resources become drained and your account moves into the red. Looking after yourself is like making a deposit and can help keep your account balanced. Keep an eye on your stress levels and take action if you feel overwhelmed and drained.

Looking after yourself is neither selfish or a luxury. It is vital if you are to stay well and able to keep on providing good quality care for your loved.

These tips have been drawn from the following resources:

Asking Questions Can Help: An aid for people seeing the palliative care team, Palliative Care Australia

Partners guide to coping with cancer, Cancer Council Queensland

Gamma Knife®

Treatment with Leksell Gamma Knife® Perfexion™

Gamma Knife® surgery

Gamma Knife® surgery is a well-established method to treat selected targets in the brain. Leksell Gamma Knife® is not a knife in the normal sense of the word. The doctor makes no incisions in your head. Instead, very precisely focused beams of radiation are directed to the treatment area in the brain. The shape and dose of the radiation is optimized to hit only the target, without damaging surrounding healthy tissue. The patient is treated in one session and can normally return home shortly after treatment.

The treatment consists of four steps:

- Step 1: Attaching the frame.
- Step 2: Imaging: CT, MRI or Angiography.
- Step 3: Treatment planning.
- Step 4: Treatment.

The treatment is completed in one visit to hospital.

Before the treatment

Before treatment your doctor will inform you about the entire procedure and you will be required to sign a consent form. Gamma Knife® surgery does not require cutting or shaving of your hair. The next step is the application of the head frame.

Securing accuracy

A key component in Gamma Knife® surgery is the stereotactic head frame.

The frame allows the doctor to accurately pinpoint the target to be treated in your brain. This lightweight frame, which is attached to your head with four pins, ensures that the radiation beams can be directed with precision to the target. The frame also prevents your head from moving during imaging and treatment procedures. Local anaesthetic is applied where the pins are to be attached.

Target localisation

After the head frame is in place, a series of images are taken using Computed Tomography (CT) and Magnetic Resonance Imaging (MRI). The CT is performed in Radiation Oncology and a nurse will escort you to the Radiology Department for an MRI. Imaging is required to determine the exact size, shape and position of the target in the brain.

Treatment planning

Once your images have been taken, you can rest while your doctor develops a very precise and accurate treatment plan. Each treatment plan is unique. The doctor, together with other specialists in the team, makes the plan in a specially designed computer and calculates how the treatment should be performed.

About the Brain Tumour Support Service

Cancer Council Queensland's Brain Tumour Support Service provides free information, support and referral to people diagnosed with a benign or malignant brain tumour, their families and friends.

The service provides:

- Information about brain tumours, treatment, support agencies and rehabilitation services.
- Referral to Cancer Council Queensland's practical support program and counselling service.
- Regular information sessions in our Brisbane office, providing opportunities to meet with other people who have been impacted by a brain tumour and hear guest speakers discuss topics of interest.
- Regular newsletters offering up-to-date information, stories and support.
- For further details on the Brain Tumour Support Service, visit: www.cancerqld.org.au/get-support/cancer-emotional-support/brain-tumour-support.



Further information and support is available at cancerqld.org.au or by calling Cancer Council 13 11 20.